Complete Summary

GUIDELINE TITLE

Family bereavement support before and after the death of a nursing home resident.

BIBLIOGRAPHIC SOURCE(S)

Research Dissemination Core. Family bereavement support before and after the death of a nursing home resident. Iowa City (IA): University of Iowa Gerontological Nursing Interventions Research Center; 2002 Oct. 46 p. [25 references]

COMPLETE SUMMARY CONTENT

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INSTITUTE OF MEDICINE (IOM) NATIONAL HEALTHCARE QUALITY REPORT CATEGORIES

IDENTIFYING INFORMATION AND AVAILABILITY

SCOPE

DISEASE/CONDITION(S)

Bereavement

GUIDELINE CATEGORY

Management

CLINICAL SPECIALTY

Family Practice Geriatrics Nursing Psychology

INTENDED USERS

Advanced Practice Nurses Nurses Other Social Workers

GUI DELI NE OBJECTI VE(S)

To provide guidelines for bereavement support of family members before and after the death of a nursing home resident

TARGET POPULATION

All family members and significant others with an attachment to a deceased nursing home resident.

INTERVENTIONS AND PRACTICES CONSIDERED

- 1. Identification of nursing home residents who are palliative/approaching end of life and assignment of Bereavement Leader
- 2. Initiation and completion of Bereavement Support Worksheet
- 3. Providing family members with information about multidisciplinary end-of-life care services when the resident becomes palliative
- 4. Providing support for the family while the resident is dying and at the time of death
- 5. Assessing the bereaved family 's risk for poor bereavement outcome
- 6. Making referrals to other resources as necessary
- 7. Coordinate signing and sending a sympathy card being to the family
- 8. Assisting the family to have closure (e.g., returning the resident's belongings and saying goodbye to other staff members at the residence)
- 9. Organizing and participating in the Memorial Service for the deceased

MAJOR OUTCOMES CONSIDERED

Risk factors for poor bereavement outcomes

METHODOLOGY

METHODS USED TO COLLECT/SELECT EVIDENCE

Hand-searches of Published Literature (Primary Sources) Hand-searches of Published Literature (Secondary Sources) Searches of Electronic Databases

DESCRIPTION OF METHODS USED TO COLLECT/SELECT THE EVIDENCE

Searches of Medline and CINAHL were performed limited to articles dated 1996-2002, human and English, and using the following keywords: bereavement, grief (combined in 23 ways with: support, program, evaluation, aged, nursing home, evidence-based, and best practice).

NUMBER OF SOURCE DOCUMENTS

27

METHODS USED TO ASSESS THE QUALITY AND STRENGTH OF THE EVIDENCE

Weighting According to a Rating Scheme (Scheme Given)

RATING SCHEME FOR THE STRENGTH OF THE EVIDENCE

The grading schema used to make recommendations in this evidence-based practice protocol is:

- A. Evidence from well-designed meta-analysis.
- B. Evidence from well-designed controlled trials, both randomized and nonrandomized, with results that consistently support a specific action (e.g., assessment, intervention or treatment).
- C. Evidence from observational studies (e.g., correlational, descriptive studies) or controlled trials with inconsistent results.
- D. Evidence from expert opinion or multiple case reports.

METHODS USED TO ANALYZE THE EVIDENCE

Review of Published Meta-Analyses Systematic Review

DESCRIPTION OF THE METHODS USED TO ANALYZE THE EVIDENCE

Not stated

METHODS USED TO FORMULATE THE RECOMMENDATIONS

Not stated

RATING SCHEME FOR THE STRENGTH OF THE RECOMMENDATIONS

Not applicable

COST ANALYSIS

A formal cost analysis was not performed and published cost analyses were not reviewed.

METHOD OF GUIDELINE VALIDATION

External Peer Review Internal Peer Review

DESCRIPTION OF METHOD OF GUIDELINE VALIDATION

Reviewed by series editor Marita G. Titler, PhD, RN, FAAN and expert reviewers Norma J. Hirsch, MD, PhD (hon), Medical Staff Affairs Coordinator, Hospice of Central Iowa, West Des Moines, Iowa; Glen R. Horst, PhD(c), Coordinator, Pastoral Care Services, Riverview Health Centre, Manitoba, Canada

RECOMMENDATIONS

MAJOR RECOMMENDATIONS

The grades of evidence (A-D) are defined at the end of the Major Recommendations.

Description of the Practice

Bereavement Support of the family member(s) can be incorporated into the care plan of a dying nursing home resident with minimal cost (Burke & Gerraughty, 1994. Evidence Grade = D) and minimal disruption to staff duties and assignments. Providing clear bereavement support interventions in the care plan gives front-line staff confidence and direction to assist family members in a palliative situation where staff often feel stressed and uncertain (Burke & Gerraughty, 1994; Johnson et al., 1993. Evidence Grade = D). Any staff member can add bereavement support interventions to the dying resident's care plan; however, usually the registered nurse takes accountability for ensuring the care plan is updated with this information.

Surveyed families indicated that 97% of the support received when their family member was dying came from the front-line caregiving staff (Davidson, 1999) (see Appendix A.1 in the guideline document). Therefore, successful and consistent implementation of bereavement support depends upon the recruitment, education, and commitment of front line workers as designated Bereavement Leaders (Johnson et al., 1993. Evidence Grade = D). Each unit/area within a nursing home requires several Bereavement Leaders (registered nurses, nurses aides, social workers, chaplains and volunteers), to ensure that at least one is available 24 hours a day, 7 days a week.

While all staff members of a nursing home have a responsibility to be compassionate to grieving family members, Bereavement Leaders have specific skills and responsibilities (Johnson et al., 1993). To adequately prepare Bereavement Leaders, an education program for the implementation of the bereavement support protocol is required. Topics should include the dying process, grief theory, communication and support skills, culturally appropriate care, how to assist families with instrumental issues (making funeral arrangements, returning for the deceased resident's belongings), and documentation of bereavement support interventions (Johnson et al., 1993). Please see Bereavement Support Training Retreat (see Appendix C.1 in the guideline document) for a sample agenda.

After recruiting and educating Bereavement Leaders (most Bereavement Team members are self-selected due to their own interest in providing bereavement care), the following steps or guidelines may be used to implement family bereavement support before and after the death of a nursing home resident.

Bereavement Leaders are intended to be the primary resource for bereavement support of family members; however, organizations may choose to assign these steps to other staff members if it would be more appropriate to the organizational or clinical context.

- 1. Ensure that all families will receive consistent bereavement support (Davidson, 1999. Evidence Grade = D).
 - Identify nursing home residents who are palliative/approaching end of life.
 - Assign a primary Bereavement Leader to approach and establish rapport with the family of a palliative resident. Optimally, the Bereavement Leader already knows the resident and family.
 - Initiate Bereavement Support Worksheet (see Appendix B.2 in the guideline document).
- 2. Prior to the death of the resident, the Bereavement Leader should provide information about end-of-life care services, and assistance in contacting these services (Davidson, 1999. Evidence Grade = D).
 - Brochures and information given at admission may be lost or forgotten in the stress of the palliative situation.
 - Family members need to receive/review information about multidisciplinary end-of-life care services when the resident becomes palliative. A sample of "Palliative Services" brochure is provided (see Appendix C.2 in the guideline document.)
- 3. Bereavement Leader provides support to the family while the resident is dying, and at the time of death (Davidson, 1999; Herth, 1990. Evidence Grade = C).
 - Examples of providing support to family members include:
 - a. Listening well is frequently a more supportive intervention than talking. Rather than worrying about "the right thing to say," focus on listening to the family members.
 - b. Spending as much time as possible in the room with the dying resident and family.
 - c. 'Checking in' frequently when not able to stay at the bedside. Staying away from the room to 'give the family privacy' often causes families to worry that staff are not available or are avoiding the dying resident.
 - d. Talking openly about the dying process and observed clinical changes.
 - e. Teaching the family to provide mouth care and other comfort measures, if the family wishes to provide 'hands on' care.
 - f. Reminding the family members that the dying person may still hear them, and encouraging the family members to talk about the dying resident, and to reminisce about good times in the past and happy memories.
 - g. Helping the family to reminisce by inquiring about pictures and mementos in the room.
 - Ensure that other Bereavement Team members provide support when the primary Bereavement Leader is not available;
 - Access pastoral care chaplain on an 'as needed' basis during the dying process and immediately following the death of a resident, to provide comfort and closure for family members, staff, and other residents.

- 4. Bereavement Leaders should assess bereaved family's risk for poor bereavement outcome (Kissane & McKenzie, 1997. Evidence Grade = B) (See Appendix B.1 in the guideline document).
 - Access additional resources (chaplain, social worker, palliative clinical nurse specialist) as necessary.
 - Make referrals to community counseling and grief support programs as necessary.
- 5. Coordinate signing and sending sympathy card (Davidson, 1999; Hutchinson, 1995. Evidence Grade = C).
 - The nursing home should ensure a supply of religious and secular sympathy cards.
 - The Bereavement Leader should obtain and sign the appropriate card and place it in a visible place where other staff members gather.
 - Bereavement Leader should encourage other staff members to sign the card and include comments and remembrances about the resident.
 - One week after the death, the Bereavement Leader ensures the card is mailed.
 - After the sympathy card is sent to the family, the Bereavement Leader completes "Bereavement Support Worksheet" (see Appendix B.2 in the guideline document) and ensures appropriate storage for later evaluation of the Bereavement Program.
- 6. Assist the family to have closure with the unit where the deceased resident lived (Davidson, 1999. Evidence Grade = D).
 - Encourage the family to call the unit/Bereavement Leader before returning for the resident's belongings.
 - Bereavement Leader is available to greet and assist family members with removal of belongings after the resident's death.
 - Bereavement Leader encourages other staff members to say goodbye to the family at this time.
- 7. Organize and participate in the Memorial Service (Davidson, 1999; Foulstone et al., 1993; Lattanzi-Licht, 1989. Evidence Grade = C).
 - Nursing homes should hold an Interfaith Memorial Service at least annually, and up to 3-4 times per year as a group remembrance of residents who have died in the months since the last memorial service. An example can be found (see Appendix C.3 in the guideline document).
 - Interfaith Memorial Services should be led by an appropriate spiritual leader. For example, nursing homes that are linked to faith-based organizations may use an internal priest, rabbi, chaplain, etc.
 - Ensure that record keeping is accurate so all bereaved families are invited to the Interfaith Memorial Service.
 - Provide a display of grief information materials and pamphlets about local grief counseling services for family members attending the Interfaith Memorial Service.
 - Strongly encourage co-residents of the deceased, staff and Bereavement Leaders to attend the Interfaith Memorial Service. Families frequently express disappointment when staff do not attend the service (Nesbitt, Hill, & Peterson, 1997; Burke & Gerraughty, 1994).

Definitions

Evidence Grading

- A. Evidence from well-designed meta-analysis.
- B. Evidence from well-designed controlled trials, both randomized and nonrandomized, with results that consistently support a specific action (e.g., assessment, intervention or treatment).
- C. Evidence from observational studies (e.g., correlational, descriptive studies) or controlled trials with inconsistent results.
- D. Evidence from expert opinion or multiple case reports.

CLINICAL ALGORITHM(S)

None provided

EVIDENCE SUPPORTING THE RECOMMENDATIONS

REFERENCES SUPPORTING THE RECOMMENDATIONS

References open in a new window

TYPE OF EVIDENCE SUPPORTING THE RECOMMENDATIONS

The type of supporting evidence is identified and graded for each recommendation (see "Major Recommendations").

BENEFITS/HARMS OF IMPLEMENTING THE GUIDELINE RECOMMENDATIONS

POTENTIAL BENEFITS

With good bereavement outcome, most pre-loss life activities are resumed, and energy is available to reinvest in/enhance the bereaved 's own life.

Subgroups Most Likely to Benefit:

Individuals identified as having the following risk factors for poor bereavement outcome:

- Deaths that are unexpected, untimely or in some way shocking
- Relationships with the deceased that were ambivalent or dependent (clinging)
- Poor family coping, characterized by high conflict, low cohesiveness, poor expressiveness
- Personal vulnerability of the bereaved (e.g., poor self-esteem, low trust in self and others)
- Previous history in the bereaved of psychiatric illness, intolerance of stress, suicidal threats or attempts
- Concurrent losses, crises or stressors, particularly problems around disrupted place of residence
- Deaths (e.g., from dementia) with prolonged caregiving and anticipatory grief, with complex relief/guilt/sorrow following the death

- Bereaved's perception that the death was preventable, or if the bereaved believes he/she had the power to prevent the death and failed to do so
- Need for psychotropics, alcohol, hypnotics, tranquilizers and antidepressants by the bereaved
- Not viewing the body of the deceased
- Limited/lack of social support. Social support has frequently been cited as an important factor in bereavement outcome.

POTENTIAL HARMS

Not stated

QUALIFYING STATEMENTS

QUALIFYING STATEMENTS

- This evidence-based practice protocol is a general guideline. Patient care continues to require individualization based on patient needs and requests.
- Bereavement support for nursing home staff members following the death of a resident is beyond the scope of this protocol.

IMPLEMENTATION OF THE GUIDELINE

DESCRIPTION OF IMPLEMENTATION STRATEGY

Evaluation of Process and Outcome Factors

Process Indicators

Process Indicators are those interpersonal and environmental factors that can facilitate the use of a protocol.

One process factor that can be assessed with a sample of Bereavement Leaders is knowledge about family bereavement support. The Family Bereavement Support Knowledge Assessment Test (See Appendix D in the guideline document) should be assessed before and following the education of staff regarding use of this protocol.

The same sample of Bereavement Leaders for whom the Knowledge Assessment test was given should also be given the Process Evaluation Monitor (See Appendix E in the guideline document) approximately one month following his/her use of the protocol. The purpose of this monitor is to determine his/her understanding of the protocol and to assess the support for carrying out the protocol.

Outcome Indicators

Outcome indicators are those expected to change or improve from consistent use of the protocol. The major outcome indicators that should be monitored over time are:

- 1. Bereavement Support Worksheet completed following the death of all residents (See Appendix B.2 in the guideline document).
- 2. Reduced or no complaints from family that staff were aloof, avoided the family/dying resident, or conveyed the death had no significance at the time of the resident's death and/or at the family's return for the deceased resident's belongings.
- 3. Family survey data/satisfaction questionnaire (See Appendix A.4 in the guideline document) indicates:
 - Bereaved family members were contacted and supported by a Bereavement Leader prior to the death of their family member in the nursing home.
 - Bereaved family members were given the information they needed regarding palliative care/palliative services at the nursing home.
 - Bereaved family members were greeted and assisted with collecting the deceased resident 's belongings.
 - Bereaved family members did receive a sympathy card signed by staff on the unit where the deceased had lived.
 - Bereaved family members were invited to the Interfaith Memorial Service.

The Family Bereavement Support Outcomes Monitor (see Appendix F in the guideline document) is to be used for monitoring and evaluating the usefulness of the Family Bereavement Support protocol in improving outcomes of families following the death of a nursing home resident. Please adapt this outcome monitor to your organization or unit and add outcomes you believe are important.

INSTITUTE OF MEDICINE (IOM) NATIONAL HEALTHCARE QUALITY REPORT CATEGORIES

IOM CARE NEED

End of Life Care Staying Healthy

IOM DOMAIN

Effectiveness Patient-centeredness

IDENTIFYING INFORMATION AND AVAILABILITY

BIBLIOGRAPHIC SOURCE(S)

Research Dissemination Core. Family bereavement support before and after the death of a nursing home resident. Iowa City (IA): University of Iowa Gerontological Nursing Interventions Research Center; 2002 Oct. 46 p. [25 references]

ADAPTATION

Not applicable: The guideline was not adapted from another source.

DATE RELEASED

2002 Oct

GUI DELI NE DEVELOPER(S)

University of Iowa Gerontological Nursing Interventions Research Center, Research Dissemination Core - Academic Institution

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GUIDELINE COMMITTEE

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FINANCIAL DISCLOSURES/CONFLICTS OF INTEREST

Not stated

GUIDELINE STATUS

This is the current release of the guideline.

GUIDELINE AVAILABILITY

Electronic copies: Not available at this time.

Print copies: Available from the University of Iowa Gerontological Nursing Interventions Research Center, Research Dissemination Core, 4118 Westlawn, Iowa City, IA 52242. For more information, please see the <u>University of Iowa Gerontological Nursing Interventions Research Center Web site</u>.

AVAILABILITY OF COMPANION DOCUMENTS

None available

PATIENT RESOURCES

None available

NGC STATUS

This NGC summary was completed by ECRI on June 12, 2003. The information was verified by the guideline developer on July 15, 2003.

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